



Volume 5, Number 1, February 2019

Governor's Council on Disability

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GCD Update

by Claudia Browner

The year 2019 has already been very exciting for the Governor's Council on Disability (GCD). GCD is involved in several committees and workgroups that promote full inclusion of individuals with disabilities. Some of those include: Emergency Management, Preparedness and Response, First Responder Disability Awareness Training (FRDAT), and the Missouri Policy Summit on Post-Secondary Education for students with I/DD.

Just last week, Governor Parson announced Missouri's selection for a technical assistance program aimed at expanding employment and training opportunities, and making **Missouri a Model Employer for individuals with disabilities**. The Governor's Council on Disability is very excited to participate in this initiative. Over the next several months, representatives from the Governor's Office and partnering state agencies, along with Paraquad and the Missouri Chamber of Commerce will work on improving employment opportunities. The full news release can be found online at

https://governor.mo.gov/press-releases/archive/missouri-track-become-model-employer

March is Cerebral Palsy Awareness Month

by Rachel Rackers

February and March are full of opportunities to help bring awareness to many different health and disability topics. All of the topics are equally as important as the next, but one is closest to my heart—Cerebral Palsy (CP). Growing up with a brother who has CP, helped shape me and choose my career path. But, it also made me want to educate others about CP and other disabilities. March is Cerebral Palsy Awareness Month and the 25th of March is Cerebral Palsy Awareness Day. Green is the color for cerebral palsy awareness, so you should wear green on more than just St. Patrick's Day!



There are about 17 million people who have Cerebral Palsy, and around 350 million people are connected to someone with CP. It is the most common childhood disability, and 1 in every 500 babies are diagnosed with CP. Cerebral Palsy doesn't fit into a one-size-fits-all box. There are several types of cerebral palsy, with many variations. No two people with the disability will have it in the exact same way. There are four types of CP: Spastic, Dyskinetic, Ataxic and Mixed. Cerebral Palsy is unique, and may have certain complications that differ in each case. It can affect body movement, muscle control, muscle coordination, muscle tone, reflex, posture, balance, fine motor skills, gross motor skills and oral motor functioning.

Photos: Rachel Rackers and her brother Greg

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Missouri Youth Leadership Forum Update

by Rachel Rackers



Rohan Murphy, a nationally recognized youth speaker, is this year's Missouri Youth Leadership Forum (MO-YLF) keynote speaker and is scheduled to speak to the delegates and alumni on Tuesday, July 16th. Rohan's story is inspiring and encourages others to achieve their goals, no matter what obstacles they may face. We look forward to having Rohan kick off our week that will be filled with various activities and opportunities for growth!

As a reminder, the dates for 2019 MO-YLF are July 16-20th and the event is held at the University of Missouri in Columbia, MO. While at MO-YLF, the delegates will gain skills, knowledge, self-confidence, and much more. It is important for the delegates to be able to apply these skills once they are back home from the forum. This year, we are adding a session on the last day for parents/guardians. During this session, we cover a variety of topics that will be helpful for parents as they support their transition-aged youth. Along with the addition of adding a parent session, we will also be incorporating several new topics throughout the week. Some of those topics are different parts of independent living (IL), history of IL, and also relationships.

Applications for delegates and volunteer staff are still being accepted and available on our website at http://disability.mo.gov/gcd/ylf.htm. The deadline for delegate applications is March 31, 2019.

If you know of a student with disabilities who has leadership potential, please share the information about this exciting program with them. GCD is looking for applicants from all areas of the state. MO-YLF is free of cost to the students who are selected. This is all made possible because of donations and sponsorships. If you or your organization would like to help us make this great program possible, please contact GCD for more information.

For questions, please contact the Governor's Council on Disability at (800) 877-8249 or (573) 751-2600.

Disability Rights Legislative Day

by Claudia Browner



The 18th Annual Disability Rights Legislative Day has been scheduled for Wednesday, March 13, 2019 in Jefferson City.

The rally is hosted by the Missouri Developmental Disabilities Council and is attended by individuals with disabilities, advocates and disability organizations to meet with legislators and bring attention to disability-related topics.

The event is held from 11 a.m. to 2 p.m. in the First Floor Rotunda of the Missouri State Capitol.

For the agenda and detailed information, please visit the DD Council's <u>website</u> at http://www.moddcouncil.org/?page_id=whatsnewstory&id=34

GCD offering Legislative Education Project

by Laura Mueth

Do you have a group of 10 or more individuals who would like to learn about the legislative process, how to communicate with legislators, and other relevant topics? The Legislative Education Project might be an option.

The Governor's Council on Disability's offerings include:

- Online videos and modules
- · A presentation in your community, and
- A day at the Capitol building in Jefferson City.

Visit https://disability.mo.gov/gcd/LEP.htm to learn more.



Groups from Kansas City, Springfield, St. Joseph, and St. Louis have already contacted our office. Yours could be next.

Meet Council Member James Trout

by Claudia Browner

James Trout was appointed to the Governor's Council on Disability in 2009. In 2011, he was elected Acting Chair of the Council and served in that capacity until 2015. To date, he continues to serve as a Council member.

James raised two sons in Webster Groves, the eldest having Williams Syndrome. "Having a son with a disability didn't make me an expert on anything other than patience with a sense of humor, but it did give me a real appreciation for a large segment of the population that interacts with our world differently than I did."

James also served as chair of the Council's Advocacy Committee and Programs Committee and took a real interest in two specific Council Goals when he joined the GCD: *Encourage system changes and public policies that eliminate barriers, and expand opportunities for independence.*

James lead two initiatives while serving as Acting Chair. The first was to develop a Council policy statement on Indoor Air Quality. The intent was to better inform and protect those with chemical sensitivities. The result, though, helps everyone stay alert to the indoor environmental toxins that cause disease and disability. The second initative was to establish uniform accessibility standards for housing built using state incentives. The Universal Design (UD) Coalition convinced the Missouri Workforce Housing Association and the Missouri Housing Development Commission to adopt UD standards for all housing built using Missouri tax credits, now incorporated in state standards.

Mr. Trout's background includes 30 years as a Designer/Builder and the last decade as an industry expert in energy efficiency and indoor environmentals.

Mr. Trout served on several boards and committees, such as the Parent Leadership Institute, Building Performance Institute, Green Builders Council (HBA), and Missouri Association of Realtors, just to name a few.



- Yvonne Wright, Chair, New Bloomfield
- Joan Bergstrom, Ed. D, Lee's Summit
- Charles Comstock, Kirksville
- Betty Davidson, Ph.D., St. Louis
- Ronald Hack, St. Louis
- Chip Hailey, Joplin
- Mary Ann Harter, St. Louis
- Rosemary Hendon, West Plains
- Katie Jones, St. Charles
- Elijah Mayfield, Jefferson City
- Todd Mayfield, Jefferson City
- DeAnna Noriega, Columbia
- Susan Orton, Creve Coeur
- Opeoluwa Sotonwa, Jefferson City
- James Trout, St. Louis
- Robert Wallace, St. Louis

Missouri Governor's Council on Disability Staff Members

- Christina Brazell, Administrative Office Support Assistant
- Claudia Browner
 Executive Director
- Laura Mueth,
 Disability Program
 Specialist
- Rachel Rackers,
 Disability Program
 Specialist

March is Cerebral Palsy Awareness Month

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A common mishap for individuals with CP, is that they are treated as if they have an intellectual disability when in reality, most people who have the condition have normal to above-average intelligence.

So what can you do for Cerebral Palsy Awareness Month? You can educate yourself and others about it. Everyone who has CP is affected so differently by it, which tends to create many rumors and misunderstandings. If you hear something that is stated wrong, politely correct the person with factual information. Lastly, I challenge you to get to know someone who has CP or any other disability.

Below are links for information regarding the other upcoming awareness events. Check them out!

Awareness Events in February

AMD/ Low Vision Awareness Month

Kids ENT Health Month

Marfan Awareness Month

Feeding Tube Awareness Week (Feb. 4-8)

Congenital Heart Defect Awareness Week (Feb. 7-14)

Duchenne Muscular Dystrophy Awareness Week (Feb. 13-19)

Donor Day and Congenital Heart Defect Awareness Day (Feb. 14)

<u>International Angelman Day</u> (Feb. 15) <u>Rare Disease Awareness Day</u> (Feb. 28)

Awareness Events in March

Brain Injury Awareness Month

Developmental Disabilities Awareness Month

Hemophilia Month

Kidney Month

Trisomy Awareness Month

Spread the Word to End the Word Day (March 7)

World Kidney Day (March 14)

World Down Syndrome Day (March 21)

Purple Day for Epilepsy Awareness (March 26)

Upcoming Events

•	March 1, 2019	Reverse Job Fair	, State Fair Community	College Osage Beach
•	Maich 1, 2019	Reverse Jud Pair	, State Fair Community	Conege, Osage Deach

• March 8, 2019 <u>Lake Area Transition Network</u>, Osage Beach

• March 13, 2019 <u>Disability Rights Legislative Day,</u> State Capitol, Jefferson City

• March 15-22, 2019 Legislative Spring Break

• April 1-2, 2019 Power Up Assistive Technology Conference & Expo, Columbia

• May 17, 2019 Last day of Missouri Legislative Session

• June 16-19, 2019 <u>National ADA Symposium</u>, Grapevine, Texas

• June 17 –20, 2019 <u>Transition Training Institute</u>, Columbia

• June 18-20, 2019 <u>National APSE Employment Conference</u>, St. Louis

• July 16-20, 2019 <u>Missouri Youth Leadership Forum</u>, MU Campus, Columbia





Volume 5, Number 2, April 2019

Governor's Council on Disability

GCD presents Annual Awards

by Claudia Browner

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The Governor's Council on Disability presented its annual Inclusion and Youth Leadership Awards at the Power Up Assistive Technology Conference and Expo on April 2 in Columbia.

The <u>Inclusion Award</u> and one Honorable Mention are presented annually to recognize private and public employers, individuals, and organizations that have successfully included people with disabilities in education, employment, housing, leisure activities, universal design, and website accessibility.



2018 Inclusion Award winner: Bloom Café, St. Louis

Bloom Café is a universally designed restaurant owned and operated by Paraquad that provides job training for adults with disabilities, and serves as a model of integrated employment. Approximately 60% of Bloom Café's staff have disabilities. In addition to the restaurant, Bloom Café provides individuals with disabilities a pathway to economic independence through a formal job training program which includes job

skills training, soft skills training and paid internships in the community as well as assistance with finding permanent jobs. Through this program, Bloom Café is promoting inclusion and equal participation for people with all types of disabilities.

(Photo: Christina Brazell, Lily Weeks, Aimee Wehmeier, Joe Wilson, Claudia Browner)

(Continued on page 2)

Legislative Education Project Success

by Laura Mueth

The <u>Legislative Education Project</u> (LEP) is wrapping up for 2019. There is one remaining in April at UMSL in St. Louis.

LEP's held in Springfield and Kansas City in February, and in St. Joseph in April were successful. The LEP in Springfield featured a great collaboration between three different area agencies to make it happen. This event had the biggest turnout with thirty-six people. Thank you to Empower: Abilities (formerly Southwest Center for Independent Living), Arc of the Ozarks, and Abilities First for encouraging people to attend. Even though the LEP in Kansas City was small in number, it was mighty. There was great discussion regarding bills and concerns. Both sides learned new things and individuals left empowered to use their voice to advocate for change.

We already look forward to providing LEP training during the next legislative session.





Laura Mueth had to say goodbye to her service dog Syler. He will be missed.

GCD presents 2018 Awards, continued

(Continued from page 1)



Honorable Mention: Jim and Theresa Edwards/Sophie's Run

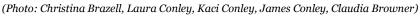
Jim and Theresa Edwards are prime examples of community leaders for students with disabilities. In memory of their daughter, the Edwards started Sophie's Run, a non-profit organization to raise funds to support families and students who need augmentative and alternative communication devices in the Park Hill School District and throughout their transition to college and post-secondary opportunities. These devices allow nonverbal students to have a voice, independence, and the opportunity to advocate for themselves and live a meaningful, purposeful life.

(Photo: Christina Brazell, Theresa Edwards, Jim Edwards, Claudia Browner)

The <u>Youth Leadership Award</u> and one honorable mention recognize outstanding Missouri youth (age 16-26) with a disability that have demonstrated exemplary leadership by making a difference in their community.

2018 Youth Leadership Award winner: Kaci Conley

Kaci Conley has dedicated much of her personal time to bring awareness to her community regarding accessibility and advocacy for individuals with disabilities. As a student at Maryville University, she joined the ABLE campus group to advocate for campus awareness and increasing accessibility features on campus. Kaci was elected co-president of ABLE and hosted a Disability Awareness event on campus, and was the only student chosen to join a faculty/student committee for accessibility for individuals with disabilities. Kaci demonstrates that her disability does not limit her ability to succeed and reach her goals. Her next goal is to ensure that the graduation ceremony is accessible to all students.







Honorable Mention: Madelyn Hubbs

Madelyn Hubbs is a dedicated advocate for all abilities. A freshman at Maryville University, she is a role model for other students, giving presentations at area schools about disabilities, prosthetic limbs, and anti-bullying. For the last ten years, Madelyn has been a patient ambassador for Shriners Hospital for Children. She has volunteered hundreds of hours working at Shriners events, raised more than \$5,000 and collected over 2,180 new toys for the children at Shriners Hospital. Madelyn has demonstrated exemplary leadership skills, won numerous awards, and is an alum of the Missouri Youth Leadership Forum. It is her goal to become an occupational therapist and make this a better world for individuals with disabilities.

(Photo: Madelyn Hubbs)

April Awareness Events

- Autism Awareness Month
- Donate Life Month
- Parkinson's Disease Awareness Month
- National Cancer Control Month

May Awareness Events

- National Arthritis Month
- Asthma and Food Allergy Awareness Month
- Mental Health Month
- Stroke Awareness Month

Inclusive Emergency Preparedness Planning

by Claudia Browner

Are you prepared for an emergency? Do you have a plan in place for yourself and your family? Have you practiced your emergency plan?

Spring in Missouri can bring severe weather, flooding and other emergencies, so now is a good time to make or review your emergency plans and prepare emergency kits with the supplies needed to survive, as well as update your emergency contacts.

The Governor's Council on Disability is involved in workgroups and trainings addressing the needs of the disability community in emergencies, including the State Emergency Management Agency's (SEMA) Access and Functional Needs Committee and the <u>First Responder Disability Awareness Training</u> (FRDAT—a program funded by the Missouri DD Council).



What if an emergency happens while you are at work? Does your place of employment have a plan in place that includes the safe evacuation of individuals with disabilities? This includes accessible signage directing individuals to evacuation routes or accessible safe areas as well as communication systems to notify first responders about the location of individuals who may need additional assistance in an emergency, and drills to practice these plans.

GCD's Disability Web Portal provides a number of resources related to <u>Emergency Preparedness and Safety</u>. To learn more and access these helpful resources, please visit our website at http://disability.mo.gov/emergency.htm

Meet Council Member Mary Ann Harter

by Claudia Browner



Mary Ann Harter (nee Gerber) is an attorney and retired teacher for the St. Louis Special School District. She holds degrees in law (J.D. cum laude St. Louis University); and English (B.A. summa cum laude) and Psychology (M.A. summa cum laude) from the University of Missouri at St. Louis. She also holds an elementary school teaching certificate from Central Methodist College and taught at St. Bridget's Catholic School in Pacific, Missouri.

In her practice of law, Mary Ann has been an assistant prosecuting attorney, assistant public defender, assistant general counsel for the Missouri Department of Revenue, in corporate practice, a research attorney for the Missouri Court of Appeals Eastern District, and has been in private practice for several decades. She volunteers to represent indigents through the Legal Services of Eastern Missouri. She also helps organize the instruction of English language to children in China over the internet with teachers in the United States.

Mary Ann has always had great interest in the disability community. Her disability of Rheumatoid Arthritis forced her to retire from active teaching. She has served on the Governor's Council for years, is a member of the council's advocacy committee and chairs the employment subcommittee.

Mary Ann lives in South St. Louis County with her husband Charles, a practicing attorney with disabilities, and children, some of whom have disabilities, and who study pre-med at Purdue University, engineering at Washington University, English at U.M.S.L. and at Lindbergh high school. She has two adult daughters, one in Potosi and a nurse practitioner in Dallas, and loves to visit her four grandchildren.

Mary Ann has served on the parish council at both St. Elizabeth's of Hungary and Our Lady of Providence in Crestwood. She is a former long standing board member of Missouri Parent Act (MPACT). She is a member of the Missouri Bar Assn, Lawyers for Life and the St. Thomas More Legal Society.

- Yvonne Wright, Chair, New Bloomfield
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Meet MO-YLF alumna Kelsey Redding

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This month's MO-YLF spotlight is on Kelsey Redding. Kelsey graduated from the <u>Missouri Youth Leadership Forum</u> (MO-YLF) this past summer, right before the start of her senior year in high school.

by Rachel Rackers

While growing up, Kelsey not only faced challenges with her disabilities, but also with being placed in foster care. Although Kelsey was up against a lot from a young age, she has always felt it was important to help others and put a smile on their faces. In the months leading up to MO-YLF, Kelsey moved into the home of pair of high school instructors. That is when the world began to open up for Kelsey.

During the MO-YLF, Kelsey realized that nothing will ever be handed to her and that she is going to have to work every day to be the successful person she wants to be, and that even with a disability, she can do anything she sets her mind to. She also realized that a barrier in her education was a lack of confidence. Kelsey has been able to achieve many things and overcome barriers in the last eight months since attending MO-YLF. She's been able to conquer fears when it comes to her school work and was able to test out of special education.

Kelsey participated in the Vocational Rehabilitation Summer Work Experience and was hired by the same employer afterwards. Since attending the Missouri Youth Leadership Forum, she has been sharing her inspirational story with the community, agencies, and students with disabilities and their parents. So far she has had the opportunity to speak at a Transition Atlas for Youth meeting, MPACT Transition Expo, school board meetings, MU Pre-ETS Boot Camp, among many others. She was also featured in VR's state-wide newsletter.

Kelsey was selected to go to Washington D.C. with the JAG (Jobs for America's Graduates) Organization. She is the Club President for JAG, a member of Advanced Choir, FCA, Writing Club, and has assisted in her church's Vacation Bible School and other projects.

Kelsey enjoys writing and has had three poems published in three different books. This last winter was an exciting time for her as she got her license and a car, and won Homecoming Queen at East Carter High School. Kelsey has been accepted into Three Rivers College in Poplar Bluff, and has applied to come back as a staff member for this year's MO-YLF. Although she isn't sure which career path she wants to take just yet, there is no doubt that she will make a difference everywhere she goes. She sees herself making a difference by showing everyone that no matter what your disability is, you can do great things. That is okay to ask for help, but it is not okay to give up. Kelsey has been a prime example as to what can happen when you take those first steps.

Kelsey is forever grateful for her teachers, her foster parents, Pre-ETS, Vocational Rehabilitation, MO-YLF, and everyone that has been a part of her journey thus far.

Upcoming Events

• April 22, 2019	Legislative Education Project (LEP), UMSL, St. Louis
• April 30, 2019	Disability Inclusion Summit, Disability:IN GKC, Kansas City
• May 17, 2019	Last day of Missouri Legislative Session
• May 17, 2019	Charting the LifeCourse for Health, Jefferson City
• June 16-19, 2019	National ADA Symposium, Grapevine, Texas
• June 17 –20, 2019	Transition Training Institute, Columbia
• June 18-20, 2019	National APSE Employment Conference, St. Louis
• July 16-20, 2019	Missouri Youth Leadership Forum, MU Campus, Columbia



Volume 5, Number 3, June 2019

Governor's Council on Disability

GCD announces Poster Contest

by Claudia Browner

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Calling all Missouri artists with disabilities! Share your talents and raise awareness about the importance of employment for people with disabilities.

National Disability Employment Awareness Month (NDEAM) is observed each year in October to celebrate the contributions of workers with disabilities and educate about the value of a workforce inclusive of their skills and talents.

The Governor's Council on Disability (GCD) has initiated a poster contest to celebrate Disability Employment Awareness Month in Missouri. The posters are intended to spark a conversation about employment of people with disabilities. Artwork for the poster is selected by a submission and judging process and is open to Missouri artists (age categories: K-12 and Adults) with a disability.

The GCD will recognize outstanding Missouri artists with a disability. The winning artwork in each age category, along with a short bio about the artist, will be featured on a poster that will be promoted statewide during the month of October.

Deadline for submissions is August 1, 2019.

For more information and to enter the contest, please see the attached flyers and visit our website at https://disability.mo.gov/gcd/PosterContest

Celebrate the ADA

by Claudia Browner



Celebrate the ADA

Show your commitment to the ADA

PLEDGE, ON!

July 26 marks the 29th Anniversary of the Americans with Disabilities Act (ADA). Here are some ideas of what you can do to celebrate the ADA and promote inclusion:

- Make sure your websites are accessible
- Provide accommodations for meetings and events
- Offer training on ADA issues on a regular basis
- Participate in online courses to learn about ADA regulations
- Exhibit works by artists with disabilities
- Demonstrate the use of assistive technology at community events

For additional ideas for Celebrating the ADA, please visit the ADA National Network's website at https://www.adaanniversary.org/ideas-celebrate-ada
You can also show your commitment to the ADA by signing the ADA Pledge.

2019 Legislative Session Concluded

by Laura Mueth



The 2019 concluded on May 17. As is customary, there was a lot of activity in the last week of the session.

A few bills important to the disability community were Truly Agreed To and Finally Passed as individual bills. These include <u>Senate Bill 101</u> which creates a statewide hearing aid distribution program, <u>House Bill 547</u> which creates treatment court divisions, <u>Senate Bill 29</u> which extends the end date of certain reimbursement allowances, and <u>House Bill 138</u> which creates Simon's law.

Several bills were added to other bills and Truly Agreed To and Finally Passed in that form.

One of those bills was a bill to repeal the all-rider motorcycle helmet law that currently exists in Missouri. Some of the other items that may be of interest to members of the disability community that were passed this way include extending the Ticket to Work

program, advanced practice nurses using telehealth, establishing a pilot program for structured family caregiving, and changing the payment calculation for sheltered workshops.

House Bill 300 and Senate Bill 230 that started as disability related bills were turned into omnibus bills. This means several bills that have related subjects were combined to get them passed. In addition to mandating health insurance coverage for children with physical disabilities, House Bill 399 includes personal care assistance vendor requirements, extension of financial assistance for Consumer Directed Services, creation of an assessment tool for home and community-based services, and offenders having MO HealthNet benefits suspended rather than terminated. Senate Bill 230 includes establishing proper venue in cases involving guardian or conservator appointment and ABLE Account assets not being part of a conservatorship estate unless they are in the charge and custody of a public administrator.

Senate Bill 514 which began as a non-disability related bill ended up having several disability related bills added to it in omnibus form. Some are ones mentioned in the above paragraphs. Others are Medicaid per diem reimbursement rate recalculation, removing the dual eligible requirement for the MO RX Plan, extension of the consumer directed services program for those who are not eligible for MO HealthNet, and suicide prevention training for marital and family therapists.

The appropriations bills which fund state government departments and programs were also Truly Agreed To and Finally Passed before the constitutionally required deadline of May 10.

All of these bills are now in the Governor's Office awaiting Governor Parson's consideration and action. As a reminder, he can sign the bill, veto the bill, or take no action. He can also do a line item veto on appropriations bills. This means he can veto specific budget items/lines while the rest is signed. Bills he chooses to not act on still become law. They are just not endorsed by him.

June Awareness Events

- Alzheimer's and Brain Awareness Month
- Scoliosis Awareness Month
- National Cancer Survivors Day (June 2)
- World Sickle Cell Day (June 19)
- Helen Keller Deaf-Blind Awareness Week (June 22-29) •

July Awareness Events

- Cord Blood Awareness Month
- Juvenile Arthritis Awareness Month
- National Cleft and Craniofacial Awareness/Prevention
- UV Safety Month
- World Hepatitis Day (July 28)

Meet Council Member Chuck Comstock

by Claudia Browner



Chuck Comstock has been an active member of the Governor's Council on Disability since 2010 and serves on the Advocacy and Programs Committee as well as the Transportation Subcommittee.

Chuck served in the U.S. Air Force and worked on his family's farm in Downing, Missouri. At the age of 20, he sustained a spinal cord injury. Using self-direction and self-determination, he earned a Bachelor of Arts degree in English from Truman State University.

From 2008 until 2017, he worked at the Kirksville Regional Office as an Advocacy Specialist and coordinated the annual *disAbility Awareness Event* at Truman State University in Kirksville. In June of 2011, he married Melissa Comstock and they now have two beautiful, energetic daughters.

Chuck is now a stay at home dad and does a lot of chores around the house. Last winter, he got very creative when he mounted a blade to his motorized wheelchair

and cleared his driveway from the snow. His invention worked so well that he decided to help out some of his neighbors by plowing their driveways. He also figured out a way to mow his lawn by attaching the lawnmower to his wheelchair. According to Chuck, "There are no limitations to what a person can do."

MO-YLF features Mentor Event and Legislative Day

by Rachel Rackers and Laura Mueth

Thirty delegates and numerous staff are getting geared up for the 17th Annual Missouri Youth Leadership Forum (MO-YLF) to be held at the University of Missouri in Columbia, July 16-20. Throughout the week, delegates will be exposed to a variety of mentors. One unique event during the week is the mentor luncheon, where many successful individuals with disabilities from a variety of different career paths are invited. It is an opportunity for delegates to talk and learn first-hand that they can lead productive and full lives.



This has been an exciting year for MO-YLF. We received the second highest number of applications in the MO-YLF history. From the 54 applications received, we selected 30 delegates and placed 6 on a waiting list. There are also roughly 20 alumni returning in staff and mentor roles this year. It is such an exciting moment, when alumni can help guide delegates to reach their full potential.

One of the days of the MO-YLF is dedicated to legislative activities at the Capitol Building in Jefferson City. The activities include a mock House Hearing on a topic voted on by the delegates, a mock floor debate in the House of Representatives, a debate/discussion in the Senate Chamber, and a visit to the Governor's Office.

The Governor's Council on Disability invites legislators to participate in the mock hearing and debates, to serve as mentors as the delegates experience the various roles of a legislator as *their* bill makes its way through the steps of the legislative process. Having legislators involved serves multiple purposes for the delegates. First, it allows them to learn from people who actually do those jobs. Second, it allows them to realize legislators are not unapproachable. Third, it allows delegates to learn about the backgrounds of the legislators and that not all of them are attorneys and that they themselves could one day be a legislator.

From the perspective of the Governor's Council on Disability, legislator involvement gives the opportunity for legislators to interact with and thus gain a greater understanding of people with disabilities. This year's legislative day is Thursday, July 18.

- Yvonne Wright, Chair, New Bloomfield
- Joan Bergstrom, Ed. D, Lee's Summit
- Charles Comstock, Kirksville
- Betty Davidson, Ph.D., St. Louis
- Ronald Hack, St. Louis
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Response to JC Tornado and Flooding

by Claudia Browner

The month of May has been a tough month for the State of Missouri between multiple tornadoes across the state, and flooding of many rivers including the Missouri and Mississippi.

Here in Jefferson City, disaster struck on May 22 on the eighth anniversary of the Joplin tornado when an EF3 tornado ripped a 3 mile path of destruction across the city, destroying several businesses, homes, and causing significant damage to some state office buildings and one school. A few days later, the Missouri river topped the levy in North Jefferson City causing significant flooding. With all the rain and storms that followed, the river has reached levels not far from the "Great Flood of 1993". The flooded streets downtown make it difficult to navigate the city. And the flooding is not over yet, with additional storms and rain in the forecast.



What's been uplifting and positive throughout these events is the quick action from emergency responders and emergency management agencies, volunteer organizations, as well as the overwhelming community outreach and support.

Multi-Agency Resource Centers were organized quickly to assist those affected by the disasters, and shelters opened up for those in need.

Jefferson City is showing its resilience as a strong community and is working hard to recover from these disasters along with the other communities throughout the state.

For individuals who still need to reach out for assistance or would like to volunteer, please visit United Way 2-1-1 at www.211helps.org or call 2-1-1.

National ADA Symposium, Grapevine, Texas

APRIL Conference, GrandRapids, Michigan

Upcoming Events

• June 16-19, 2019

• Oct. 25-28, 2019

• June 17 –20, 2019	Transition Training Institute, Columbia
• June 18-20, 2019	National APSE Employment Conference, St. Louis
• July 16-20, 2019	Missouri Youth Leadership Forum, MU Campus, Columbia
• Sept. 23-25, 2019	National Head Injury Conference, Kansas City



Volume 5, Number 4, August 2019

Governor's Council on Disability

New Council Members Appointed

by Claudia Browner

The Governor's Council on Disability is excited to announce its newest Council members!

On July 9, 2019, Governor Parson appointed three new Council members to the Governor's Council on Disability—Kim Lackey, who serves as the Director of Public Policy and Advocacy at Paraquad Inc., a Center for Independent Living in St. Louis; Andrew Sartorius, an attorney with Sartorius Kirsch in Jefferson City; and Lesia Shelton, a Specialized Employment Manager with Preferred Employment Services in Springfield. Congratulations on your appointments.

We will introduce our new Council members in the upcoming issues of the GCD Newsletter. This current issue features Kim Lackey in our <u>Council member spotlight</u> on Page 3.

Thirty New Leaders Graduate MO-YLF

by Claudia Browner

GCD staff and planning team members from our partnering agencies spent the last several months preparing for the 17th annual Missouri Youth Leadership Forum (MOYLF), a week-long leadership and career development training for high school students (ages 16-21) with disabilities. The turnout was the highest ever with 30 delegates participating in the event, along with many staff members and volunteers who helped make this year's MO-YLF another great success. A special thank you goes to Paraquad, MU Pre-Employment Transition Services, and the Division of Vocational Rehabilitation for their involvement in the planning and staffing of the event, as well as all of the sponsors and donors who make this program possible.



Photo: 2019 Missouri Youth Leadership Forum delegates and staff on MU campus

From July 16-20, thirty delegates representing 21 different counties in Missouri learned about the importance of self-advocacy, disability culture and history, mentorship, the legislative process in Missouri, career development, independent living and community service. Throughout the week, delegates completed a leadership plan by setting goals for their future.

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Missouri Youth Leadership Forum, continued

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Photos: (left) Adaptive Sports Night—(center) Mentor Event—(right) Employment/Career Development Event- (below) MO-YLF participants and Governor Parson in the Governor's Office

One of the highlights of the week was the legislative day at the capitol, where delegates engaged in a mock legislative debate in the House and Senate Chambers, led by Representatives Chuck Basye, Ian Mackey and legislative liaison Rich



Germinder (Dept. of Natural Resources) in the House, and Senator Lauren Arthur in the Senate.

Following the mock bill debate, the MO-YLF participants had the opportunity to visit the Governor's Office and meet Governor Parson. This experience left a lasting impression for many of the delegates!

Evening activities included national keynote speaker Rohan Murphy, an adaptive sports night led by Disabled Athlete Sports Association (DASA), a talent show, and a dance.

On the last day of MO-YLF, parents had the opportunity to attend an educational session and resource fair. At the closing graduation banquet, the delegates gave presentations about

their learning experience to the audience, and graduated to become MO-YLF alumni. Since the inception of the program in 2001, 344 delegates have completed the program. Sixteen of the MO-YLF alumni also returned this year to serve as facilitators, team members and mentors.

The planning team will soon start preparing for next year's MO-YLF. Be sure to watch for announcements and the application this fall and help us share the information about this life changing program.

August Awareness Events

- <u>Children's Eye Health and Safety Month</u>
- <u>Gastroparesis Awareness Month</u>
- National Immunization Awareness Month
- Psoriasis Awareness Month

September Awareness Events

- Cancer Awareness Month for <u>Childhood</u>, <u>Ovarian</u>, <u>Prostate</u>, and <u>Blood</u> Cancers
- National Preparedness Month
- National Sickle Cell Month
- National Suicide Prevention Month

Click on the links for more information!

Meet Council Member Kim Lackey

by Claudia Browner



One of the three newest appointees to the Governor's Council on Disability is Kim Lackey, who was appointed by Governor Parson on July 9, 2019.

Kim Lackey is the Director of Public Policy and Advocacy at Paraquad Inc., a Center for Independent Living in St. Louis. At Paraquad, Kim leads the policy and advocacy strategy for the organization. She guides and directs a team of individuals working to influence public policy and create change that improves the lives of individuals with disabilities. Kim performs policy research and analysis, legislative advocacy, and legal advocacy. She attended the University of Missouri-Columbia and received a B.S. in History and Political Science. Kim graduated from the University of Missouri-Columbia, School of Law in May 2006 with her J.D.

Kim has worked on improving access to employment, health care, public transportation and affordable accessible housing for individuals with disabilities for more than 12 years. Kim and her husband Andrew live in St. Louis.

Legislative Actions and Upcoming Priorities Poll

by Laura Mueth

Governor Parson has signed several bills since the conclusion of the legislative session. He signed all of the appropriations bills without any line item vetoes. This means the state budget was funded as passed by the House of Representatives and Senate. Signed bills related to disability include House Bills 138 and 547 and Senate Bills 29, 101, 230, and 514. All signed bills will go in to effect later this month on August 28 unless another date is specified. For details regarding each bill please see the "Legislative Session Concluded" article in the June issue of the GCD Newsletter and the Legislative Update.

Governor Parson vetoed two bills with sections related to disability issues. House Bill 399 was one but several parts of it are also part of Senate Bill 514 and will become law as a result of Senate Bill 514 being signed. The other was Senate Bill 147 which means the all-rider motorcycle helmet law will not be repealed and remains law in Missouri. You can read the veto letters at House Bill 399 Veto Letter and Senate Bill 147 Veto Letter.



At the conclusion of legislative sessions individuals with disabilities and organizations often reflect on the accomplishments from the session and work that still needs to be done to improve lives and make Missouri a state people are proud to call home.

If you believe more needs to be done by state legislators to improve the lives of people with disabilities please complete the Governor's Council on Disability's upcoming 2019 Legislative Priorities Poll between August 26th and November 8th.

For those not familiar with the Legislative Priorities Poll and its purpose, each year GCD sends out a poll to hear from the public regarding disability related legislation and areas of concern. Each response received is reviewed by staff and will be used to shape the Council's legislative priorities and interactions with legislators for the 2020 legislative session. A report of the results is also shared with all legislators and other elected officials.

The Legislative Priorities Poll will be available on August 26th on the <u>Legislative Priorities Poll page</u> of the GCD website and at events. The online survey link will also be sent to the GCD email lists and posted on Facebook.

- Yvonne Wright, Chair, New Bloomfield
- Joan Bergstrom, Ed. D, Lee's Summit
- Charles Comstock, Kirksville
- Betty Davidson, Ph.D., St. Louis
- Ronald Hack, St. Louis
- Chip Hailey, Joplin
- Mary Ann Harter, St. Louis
- Rosemary Hendon, West Plains
- Katie Jones, St. Charles
- Kim Lackey, St. Louis
- Elijah Mayfield, Jefferson City
- DeAnna Noriega, Columbia
- Susan Orton, Creve Coeur
- Andrew Sartorius, Jefferson City
- Lesia Shelton, Buffalo
- Opeoluwa Sotonwa, Jefferson City
- James Trout, St. Louis
- Robert Wallace, St. Louis

Missouri Governor's Council on Disability Staff Members

- Claudia Browner,
 Executive Director
- Christina Brazell, Administrative Office Support Assistant
- Laura Mueth,
 Disability Program
 Specialist
- Rachel Rackers,
 Disability Program
 Specialist

MOSILC Consumer Needs Survey



The Missouri Statewide Independent Living Council (MOSILC) is asking for your participation in the annual Missouri Statewide Consumer Needs Survey 2019.

The information is used to develop the next three year State Plan for Independent Living (SPIL).

To complete the survey, please visit https://www.surveymonkey.com/r/L8K5RHN

For questions or additional information, please contact MOSILC at https://mosilc.org

ADA 2020 Impact Survey

The year 2020 will mark the 30th anniversary of the Americans with Disabilities Act (ADA).

A research study is currently underway to study the impact of the ADA 30 years after its passage. You can help!



ADA 2020 Impact Survey

Complete the ADA Impact Survey and share the survey link: http://sgiz.mobi/s3/ADA-Impact-2020-Survey

Upcoming Events

• August 13, 2019

• Oct. 25-28, 2019

8 0, 1	
• August 25-27, 2019	Real Voices Real Choices Conference, Osage Beach
• September 10, 2019	The Arc Missouri Educational Summit, Columbia
• Sept. 23-25, 2019	National Head Injury Conference, Kansas City
• October 2, 2019	MPACT Tools for Life Transition Summit, Joplin
• October 15, 2019	MPACT Tools for Life Transition Summit, Jefferson City

APRIL Conference, GrandRapids, Michigan

Mental Health Champions Banquet, Jefferson City





Volume 5, Number 5, October 2019

Governor's Council on Disability

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- **Recognizing Leaders** in the Disability Community

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- **Meet Council Member Lesia Shelton**
- **Awareness Events**

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- **Upcoming Events**



National **D**isability **Employment** Awareness Month

October is National Disability Employment **Awareness Month**

by Claudia Browner

National Disability Employment Awareness Month (NDEAM) is observed nationwide during the month of October in celebration of the contributions of workers with disabilities to the workforce. 2019 Disability Employment Awareness Month

To raise awareness and spark conversation about the importance and value of an inclusive workforce, the Governor's Council on Disability initiated the **Disability** Employment Awareness Month Poster Contest. The winner of the 2019 contest is Ashley Gillespie of Willard, Missouri. The winning poster and information about the contest can be found online at https:// disability.mo.gov/gcd/PosterContest/

Other activities during the month of October include:

- The Governor's Council on Disability's NDEAM Exhibit in the Truman State Office Building (2nd floor) in Jefferson City
- The Missouri as a Model Employer Talent Showcase for job seekers with disabilities
- Several high school transition fairs throughout the state including the MPACT Tools for Life Transition Summit in Jefferson City
- The Missouri DD Council's Invite Your Legislator to Work program

Missouri As A Model Employer Initiative

by Claudia Browner

Governor Mike Parson signed Executive Order 19-16 on September 9, 2019, announcing the Missouri as a Model Employer Initiative. The initiative is intended help more people with disabilities obtain competitive, integrated employment and directs the Missouri state government to serve as a Model Employer of individuals with disabilities through improved recruitment, hiring, and retention strategies.



To help launch the initiative, the Missouri as a Model Employer Talent Showcase will be held October 10, 2019 in the State Capitol in Jefferson City. The talent showcase is a reverse career fair that provides individuals with disabilities the opportunity to seek employment with state agencies or community employers.

Information about the Missouri as a Model Employer initiative can be found online at https://disability.mo.gov/model-employer.htm

What are Your Legislative Priorities?

by Laura Mueth



The Governor's Council on Disability wants to hear from you! The 2019 Legislative Priorities Poll is now available for completion. The GCD staff and council members encourage every Missouri citizen impacted by disability to complete it and tell us your priorities. Each response received is reviewed by staff and will be used as we shape the Council's legislative priorities and interactions with legislators for the 2020 legislative session. It is crucial that we hear **YOUR** thoughts.

Missouri is a state of diversity. Each person has ideas, concerns, and opinions. We want to ensure we hear voices from every county in this state. Help us hear those voices by completing the Poll and sharing it with others.

The Legislative Priorities Poll can be completed online at https://www.surveymonkey.com/r/QNRSVQ2.

It is also available in PDF formats which can be filled out

electronically or printed and completed by hand. These versions can be accessed at http://disability.mo.gov/gcd/legislative_priorities_poll.htm or by contacting the GCD office at 800-877-8249.

Please return all Polls by **Friday**, **November 8**, **2019 at 5:00**. Hard copies can be returned via fax (573-526-4109), email (gcd@oa.mo.gov), or mail (Governor's Council on Disability, 301 West High Street, Room 620, PO Box 1668, Jefferson City, MO 65102-1668). Assistance with completion is also available by contacting the GCD office.

Recognizing Leaders in the Disability Community

by Claudia Browner

The Governor's Council on Disability (GCD) recognizes leaders in **Inclusion** and **Youth Leadership** through its annual awards programs and is accepting nominations now for the 2019 GCD Awards.

We need to hear from you about the leaders in your communities!

Please nominate Missouri residents, organizations agencies or businesses that demonstrate excellence in leadership in the inclusion of people with disabilities in education, employment, housing, leisure activities, universal design or website accessibility for the <u>Inclusion Award</u>.

For the <u>Youth Leadership Award</u>, GCD is seeking nominations of youth with a disability that demonstrate exemplary leadership by engaging in social activism or activities that improve the quality of life of people with disabilities in their communities in Missouri.

Visit the awards programs online for more information and the nomination forms:

Inclusion Award: https://disability.mo.gov/gcd/inclwin.htm

Youth Leadership Award: https://disability.mo.gov/gcd/youthleadershipaward.htm

How can you submit your nomination? It's quick and easy—complete and submit the nomination form online, or, print and mail/fax the nomination, or complete it electronically and submit by email. If you need assistance, please contact the GCD office at 573-751-2600.



Meet Council member Lesia Shelton

by Claudia Browner

Lesia Shelton was appointed as a Council member to the Governor's Council on Disability on July 9, 2019.

Ms. Shelton has been employed with Preferred Employment Services in Springfield, Missouri since 2001, where she manages the specialized employment programs for the Deaf and Hard of Hearing and Blind and Low Vision.

Ms. Shelton grew up on a rural Missouri farm with family members who are deaf, including her mother, whose hearing deteriorated to profound hearing loss later in life. Her nephew, who lived in the same home, is profoundly deaf since birth, and was one of the reasons she chose a career specializing in service to the Deaf Community.

Ms. Shelton pursued education with Drury University, Missouri State University, and William Woods University. She completed training through the State of Missouri to serve individuals with minimal language skills and received certification as a

Communication Development Specialist. She continues her education through independent study and mentorship from members of the Deaf Community.

Ms. Shelton advocated and served as a consultant during development of an exclusive Independent Supported Living (ISL) program for the Deaf. In 2010, she learned of a producer, Hilari Scarl, in California filming a documentary of four deaf entertainers. She coordinated with Ms. Scarl to bring the film, See What I'm Saying, to Springfield, Missouri for a community screening. Outreach projects Ms. Shelton is, or has been involved with, include Deaf Awareness Group of Southwest Missouri, Horses of Hope, Domestic Violence Task Force, and Excel Alternative School for at risk youth. In addition to providing vocational services to individuals in their communities, she provides consulting and referral services for rural school districts, emergency responders, law enforcement, and business leaders.

Ms. Shelton recognizes that any activity or community encounter is an opportunity to advocate and improve awareness for the Deaf Community, and for individuals with disabilities. Her goal is to serve in a way that empowers individuals to achieve independence.

October Awareness Events

National Disability Employment Awareness
Month

Breast Cancer Awareness Month

Down Syndrome Awareness Month

National Bullving Prevention Month

Liver Cancer Awareness Month

November Awareness Events

Alzheimer's Disease Awareness Month

COPD Awareness Month

American Diabetes Month

Family Caregivers Month

Epilepsy Awareness Month

- Yvonne Wright, Chair, New Bloomfield
- Joan Bergstrom, Ed. D, Lee's Summit
- Charles Comstock, Kirksville
- Betty Davidson, Ph.D., St. Louis
- Ronald Hack, St. Louis
- Chip Hailey, Joplin
- Mary Ann Harter, St. Louis
- Rosemary Hendon, West Plains
- Katie Jones, St. Charles
- Kim Lackey, St. Louis
- Elijah Mayfield, Jefferson City
- DeAnna Noriega, Columbia
- Susan Orton, Creve Coeur
- Andrew Sartorius, Jefferson City
- Lesia Shelton, Buffalo
- Opeoluwa Sotonwa, Jefferson City
- James Trout, St. Louis
- Robert Wallace, St. Louis

Missouri Governor's Council on Disability Staff Members

- Claudia Browner, Executive Director
- Laura Mueth,
 Disability Program
 Specialist
- Rachel Rackers,
 Disability Program
 Specialist
- Vacant, Administrative Office Support Assistant

Dates Set for 2020 MO-YLF

MISSOURI TOUTH
LEADERSHIP
FORUM

by Rachel Rackers

The Missouri Youth Leadership Forum (MO-YLF) planning committee is already gearing up for 2020 MO-YLF, which will be held July 14th-18th at the University of Missouri Columbia campus.

Applications for staff, volunteers and delegates will be available by mid-

October. The deadline for delegate applications is March 31st and staff applications are due May 1st.

The MO-YLF planning committee encourages you to spread the word about MO-YLF and to come experience this life-changing week!

For more information and the online application, please visit http://disability.mo.gov/gcd/vlf.htm

Throughout the year, the MO-YLF alumni have the opportunity and are encouraged to expand their leadership skills by participating in MO-YLF panel presentations and transition fair exhibit booths throughout the state as well as promoting the program in their schools and communities.

At the Governor's Council on Disability's quarterly Council meeting in August, three MO-YLF alumni joined program coordinator Rachel Rackers in a panel presentation about the program, providing testimonials about the program's impact on their lives.

Photo: Rachel Rackers and MO-YLF alumni Andrew Sartorius, Piper Earhart and Zamira McConnell present to the Council.



Upcoming Events

• October 1-31, 2019 National Disability Employment Awareness Month exhibit,

Truman State Office Building, Jefferson City

• October 2, 2019 MPACT Tools for Life Transition Summit, Joplin

• October 10, 2019 <u>Talent Showcase Career Fair</u>, Jefferson City

• October 15, 2019 MPACT Tools for Life Transition Summit, Jefferson City

• October 17-18, 2019 MACDDS Annual Conference, Columbia

• Oct. 25-28, 2019 APRIL Conference, GrandRapids, Michigan

• October 30, 2019 Equity in Missouri Higher Education Summit, Columbia



Volume 5, Number 6, December 2019

Governor's Council on Disability

GCD Update

by Claudia Browner

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Page 3:

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- Meet Council Member Andrew Sartorius

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- Remembering MO-YLF alum Mitchell Herndon
- Upcoming Events



The Governor's Council on Disability wishes all our readers a very Merry Christmas, Happy Holidays, and a Peaceful and Healthy New Year!

The year 2019 has been eventful and productive for GCD, and we are looking forward to continuing our work and starting some new programs and initiatives as we begin a new decade in 2020.

The last few months have brought some changes to our office. In October, GCD moved to a new space on the 6th floor of the Truman building in Jefferson City. Stop by for a visit when you are in town.

We also hired a new staff member—Jessica Zimmer, who joined our team on October 16 as the Administrative Office Support Assistant for our agency.





As the year 2019 is coming to an end, we want to recognize individuals and organizations who have promoted and advocated for full inclusion of people with disabilities in all aspects of community living. We need your help to hear about individuals or organizations who deserve recognition for their efforts in inclusion and youth leadership. The 2019 GCD Awards for Inclusion and Youth Leadership will be awarded at the Power Up conference in Columbia.

Please help us **recognize leaders in the disability community** by submitting your nominations by January 31, 2020.

Did you know...?

December 3 is International Day of People with Disabilities

Promoted by the United Nations since 1992, the International Day of People with Disabilities is observed on December 3 each year to raise understanding of people with disabilities and encourage their dignity, rights and well-being.

December 10 is International Human Rights Day

Adopted by the United Nations General Assembly in 1948, Human Rights Day was proclaimed as a "common standard of achievement for all peoples and nations" and is observed annually on December 10.



MO-YLF Program and Alumni Updates

by Rachel Rackers



The planning committee for the <u>Missouri Youth Leadership Forum</u> (MO-YLF) has already begun putting things in place for the next year's Forum. The 18th annual Missouri Youth Leadership Forum will be held July 14-18, 2020 at the University of Missouri, Columbia.

Last year's MO-YLF had several expansions and firsts in the program's history. One of which, was the number of delegates who attended the five day leadership training. There were 30 delegates

who participated and graduated to become alumni. For 2020, we are planning on increasing the number of accepted delegates to 36. MO-YLF is an excellent opportunity for high school students in transition to realize their full potential. It's exciting to be able to expand and offer this life changing opportunity to more youth in Missouri.

Another change from last year that will be continued this year is a parent session before Saturday's graduation. There will be additional agencies and information provided during this year's parent session. It is an excellent opportunity to connect, inform, and educate parents/guardians on how to help their delegate during transition and to learn about what resources and agencies are available to assist with their needs after they return home.

An additional change that will continue from last year was to the leadership plan each delegate completes during MO-YLF. The new approach is more hands on with creating a vision board poster for their good life and what that might look like to them. It is broken down in such a way that allows them to identify possible barriers that could occur and what resources are available to help along the way. They also identify details on what steps are needed now and in the future to reach their goals. As MO-YLF continues to grow each year, so will the resources and opportunities that we can offer to delegates, staff and parents.



One of the greatest parts about the Missouri Youth Leadership Forum is watching alumni take leadership skills and self-determination away the Forum, and seeing how

they use these skills to be leaders in their community. There are way too many positive outcomes and transformations to list them all, but here are some most recent ones: One alumna was named a Patient Ambassador for Shriners Hospital, among other accomplishments. One alumnus was recently appointed as a council member for the Governor's Council on Disability. Another alumna has been advocating to

make her college campus and community accessible, with great success. Many alumni have either recently moved into their own place, got their first job, or were accepted into college. There have also been numerous alumni who have promoted MO-YLF by giving a presentation or participating in a panel.



It is important for all alumni to remember that their accomplishments not only have an impact in their own lives, but for other individuals that have disabilities. As they are leading by example, they are making a difference and encouraging others to see their own potential, whether they realize it or not. Keep up the great work, alumni!

For more information about the Missouri Youth Leadership Forum, please visit our website at http://disability.mo.gov/gcd/ylf.htm

Applications for staff, volunteers and delegates are now available on our website.

The application deadlines are March 31, 2020 for delegates and May 1, 2020 for staff.

The MO-YLF planning committee encourages you to spread the word about MO-YLF and to come experience this life-changing week!

Preparing for the Legislative Session

by Laura Mueth

GCD recently conducted its annual <u>Legislative Priorities Poll</u> to determine the level of importance disability related issues have to Missourians impacted by disability through their personal and/or professional lives. Thank you to everyone who participated. The results have been shared with members of our Council, legislators, executive branch staff, the GCD listservs, and social media. The Council uses the results from the Poll which included 453 responses from individuals in 36 counties to determine our legislative priorities for the 2020 session. They are:

- ⇒ The increasing cost of medication
- ⇒ All public buildings having evacuation plans for all people with disabilities
- ⇒ Private insurance coverage requirement for hearing aids
- ⇒ Health care/medical services access
- ⇒ Schools having a restraint and seclusion policy



The complete Legislative Priorities Poll Report can be accessed at https://disability.mo.gov/gcd/files/2019-Legislative-Priorities-Poll-Report.pdf. These priorities will help guide our efforts as the legislative session activities get under way in December and January. Legislators and their staff are already working on bills to introduce during the pre-filing period (December 2, 2019 to January 7, 2020). The work of getting new bills to become law begins at 12:00 p.m. on January 8, 2020 with the official start of the 2020 legislative session.

If you need assistance understanding the legislative process or how to work with your legislators, please consider participating in GCD's <u>Legislative Education Project (LEP)</u>. It provides an opportunity for individuals to receive training on these topics through videos and narrated PowerPoints, local presentations with a GCD staff member, or presentations with a GCD staff member at the Capitol. If you would like more information about the LEP, you can find it at https://disability.mo.gov/gcd/LEP.htm.

If you understand how to communicate and advocate but need some assistance keeping track of the hundreds of disability bills each session, you might consider signing up to have the <u>Legislative Update</u> sent to your email weekly during the legislative session. To sign up to receive the Legislative Update, contact Laura at <u>Laura.Mueth@oa.mo.gov</u>.

Meet Council Member Andrew Sartorius

by Claudia Browner

Andrew Sartorius was appointed to the Council on July 9, 2019. Andrew follows in the footsteps of his father Joseph, who served on the Council from 2002—2010.

A St. Louis native, he attended the Missouri Youth Leadership Forum during his junior year of high school in 2004. After graduating from Lindbergh High School, he studied biology at Rockhurst University in Kansas City and was working towards his Master's degree in molecular biology when he decided to follow his true calling—the practice of law

Andrew graduated from University of Missouri—Kansas City School of Law in 2013 and attended the Trial Lawyer's College in Jackson Hole, Wyoming. He moved to Jefferson City and worked as an assistant public defender for the State of Missouri until 2017, when he joined as a partner of Jefferson City based law firm Sartorius Kirsch.

Andrew teaches as an assistant professor of Criminal Justice and Political Science at Lincoln University, where he will instruct on state and local government next semester. He has continued his disability awareness and advocacy efforts through participation in the Missouri Youth Leadership Forum as a staff member, mentor, and panel speaker.

Andrew, his wife Katherine, and their son AJ reside in Jefferson City.

- Yvonne Wright, Chair, New Bloomfield
- Joan Bergstrom, Ed. D, Lee's Summit
- Charles Comstock, Kirksville
- Betty Davidson, Ph.D., St. Louis
- Ronald Hack, St. Louis
- Chip Hailey, Joplin
- Mary Ann Harter, St. Louis
- Rosemary Hendon, West Plains
- Katie Jones, St. Charles
- Kim Lackey, St. Louis
- Elijah Mayfield, Jefferson City
- DeAnna Noriega, Columbia
- Susan Orton, Creve Coeur
- Andrew Sartorius, Jefferson City
- Lesia Shelton, Buffalo
- Opeoluwa Sotonwa, Jefferson City
- James Trout, St. Louis
- Robert Wallace, St. Louis

Missouri Governor's Council on Disability Staff Members

- Claudia Browner,
 Executive Director
- Laura Mueth,
 Disability Program
 Specialist
- Rachel Rackers,
 Disability Program
 Specialist
- Jessica Zimmer, Administrative Office Support Assistant

Remembering MO-YLF alum Mitchell Herndon

by Claudia Browner

The Missouri Youth Leadership Forum lost one of its alumni—Mitchell Herndon. As we mourn the passing of such a charismatic and outgoing young leader, we will remember him as a very brave, courageous young man with an affectionate smile and a great sense of humor. Mitchell had such a positive attitude, a passion for advocating, and an ability to bring smiles wherever he went.



Mitchell participated in the Missouri Youth Leadership Forum in 2016, where he played a large part in the legislative day at the capitol. He enjoyed engaging with the legislators and advocating for people with disabilities.

Mitchell was elected student council president at Affton High School. His campaign slogan was, "Taking a stand for you!" which carried a special meaning for Mitchell.

He was a very intelligent young man, receiving a 32 on his ACT and being awarded the presidential scholarship for a full ride to St. Louis University. Majoring in political science, his goal was to be a lawyer.

In January 2019, he participated as an amateur lobbyist for the day and advocated for disability rights at the Missouri state capitol, where he met Governor

Parson.

Mitchell was diagnosed with a disease so rare it did not have a name and until recently, there was only one other person in the world diagnosed with this disease. The first symptoms showed up around age 12. Over the years, Mitchell was in and out of the hospital. Along with hearing and vision loss, he lost the ability to walk several times, forcing him to learn to walk again after each relapse, but Mitchell never gave up hope.



Mitchell was always eager to help medical professionals and was hoping a cure for his disease would be found in his lifetime. His health took a turn for the worse and Mitchell passed away October 2, 2019, but his legacy lives on.

NBC News aired a documentary about Mitchell that can be found at https://www.nbcnews.com/news/us-news/teen-had-disease-so-rare-it-didn-t-have-name-n1063656

Upcoming Events—Save the Dates

January 8, 2020 Missouri Legislative Session Begins
 February 7, 2020 GCD Quarterly Council Meeting, Jefferson City

• March 23-27, 2020 Legislative Spring Break

• March 30-31, 2020 Power Up Assistive Technology Conference & Expo, Columbia

• May 1, 2020 GCD Quarterly Council Meeting, Jefferson City

• May 15, 2020 Last Day of Legislative Session

• June 18-21, 2020 Career and Advocacy Forum for the Deaf/HH, MSD, Fulton

• July 14-18, 2020 <u>Missouri Youth Leadership Forum</u>, MU Campus, Columbia